

## HIV and Hepatitis Community Planning Group

### DRAFT - Meeting Minutes

September 12, 2019

<b>HIV &amp; HEPATITIS COMMUNITY PLANNING GROUP MEMBERS</b>					
*in attendance					
Julie Baker	x	Daniel Hoffman-Zinnel		Carter Smith	x
Donald Baxter	x	Steven Kleppe		Samantha Smith	x
Sue Boley	x	Douglas LaBrecque	x	Conner Spinks	x
Colleen Bornmueller	x	Roger Lacey	x	Roma Taylor	x
Megan Campbell	x	Biz McChesney	x	Pamela Terrill	x
Tim Campbell		Jeffery Moore	x	Mark Turnage	
Kathryn Edel	x	Sara Peterson		Kathy Weiss	
Linnea Fletcher		Marty Reichert		Samantha Willey	x
Greg Gross		Claudia Robinson		Corey Young	x
Holly Hanson	x	Sarah Ziegenhorn		Daniel Hoffman-Zinnel	x
LeeVon Harris	x	Jordan Selha	x		
Tami Haught	x	Michelle Sexton	x		
<p><b><i>Iowa Department of Public Health: Cristie Duric, Katie Herting, Darla Peterson, Annie Rodruck, Ariel Langtimm, Jenna Sheldon, Mary Hightower, Randy Mayer</i></b></p>					
<p><b><i>Guest(s): John Carstensen, David Lauritzen, Roger Bishop, Earthleen Canady, Kurt Berke, Vanessa Leji, Lydia Guy-Ortiz, Noah Beacom, Ashlee Folsom, Pam Bloomer-Pinkson, Angela Speers, Sarah Hambright</i></b></p>					

## Call to Order

Biz McChesney called the meeting to order at 9:00 a.m.

## Roll Call

Roma Taylor facilitated roll call.

## Ground Rules and Agenda Review

Biz reviewed the group agreements, the agenda, and the handout folder contents.

1. Membership Orientation Bylaws and Engagement Committee (MOBE) Update
2. Community Planning Group (CPG) History
3. Cluster and Outbreak Detection and Response
4. The 100ish Acronyms that You Should Know Working in HIV in Iowa
5. Our Words Matter
6. Words Matter: Health Equity Terminology
7. HIV Language Matters

## Approval of June Minutes

Roma Taylor facilitated the approval of the June minutes. No corrections or additions were made. Roger Lacey motioned to approve the minutes. Jordan Selha seconded the motion. Motion carried. Minutes were approved.

## Review of June Check-outs

Roma Taylor facilitated the review of the June check-outs. No corrections or additions were made.

## Updates and Unfinished Business

### *Bureau Update*

Presented by Randy Mayer

Randy announced the hiring of the new director of the Division of Behavioral Health, Dr. Jeff Kerber, who will start in October. Dr. Kerber will replace Kathy Stone, who retired.

The HIV Surveillance Officer and the ADAP Benefits Specialist positions within the Bureau of HIV, STD, and Hepatitis are being filled. Interviews have been completed for both positions and negotiations have begun for the ADAP Benefits Specialist. The Health Equity Coordinator position is still vacant.

There are several members of the HIV Special Projects Division who have left their positions, including Heather Smith, who finished her work on the vulnerability index assessment project, and Richard Nesselroad, who focused on drug user health. Joe Caldwell, Drug User Health Coordinator, and Dustin Wagner, HIV Special Projects Manager, have both resigned and will be leaving at the end of September 2019.

Other positions that could help with initiatives have been discussed, including a Behavioral Health Coordinator, Prevention Services Specialist, Capacity Building Specialist, and a Budget Specialist. However, the positions are pending until more is known about the budget. At this time, we will move forward only with the HIV Special Projects Manager and a position to focus on drug user health (because it is funded partially by the Bureau of Substance Abuse).

The Bureau of HIV, STD, and Hepatitis received the grant award for Ryan White (RW) Part B Supplemental. It is \$4.6 million (\$6.1 million less than we received the prior year). Randy and Holly Hanson both commented that initiatives have been implemented knowing that funding would likely be reduced over time. Additionally, projects currently supported by the RW Supplemental grant may now be supported with rebates or the AIDS Drug Assistance Program (ADAP) Emergency Relief Fund grant (due in early November). Randy also mentioned that some funding earmarked for the President's Ending the HIV Epidemic Plan may eventually be up for redistribution beyond the 57 jurisdictions identified in phase I, which may afford some opportunities.

Randy provided an update on Iowa's participation in a learning lab hosted by the National Governors Association (NGA). The Iowa team (which included legislators, a representative from the governor's office, a law enforcement representative, the IDPH, and Medicaid) traveled to New Mexico to learn about their longstanding comprehensive harm reduction services program. One take-away from the trip was that Iowa should continue to make the case for syringe services programs using data and local, community-level testimonials. The group was particularly interested in areas in Iowa where proper syringe disposal was problematic. Building support among law enforcement also needs to be emphasized. Programs such as Kentucky's that have support from law enforcement may be a model to emulate. The next steps on the team's action plan is to hold a call to review state models, such as Kentucky's, and potentially draft legislation.

Douglas LaBrecque asked how the legislators were selected for the trip. Randy replied that the chairs of the Human Resources Committees of the legislature were selected. These legislators would likely be key to passage of a public health-supported bill.

Biz McChesney asked if Medicaid treatment expansion is being included in the discussion. Randy replied that expanding treatment access within Medicaid is not in the action plan. Randy added that Medicaid's fibrosis score treatment restrictions have been reduced, but funding still

needs to be addressed to expand treatment access further. The representative from Medicaid was highly engaged in the process, though.

Ashlee Folesom asked what the best way is to share community stories and testimonials. Randy replied that this information can go to him. Conner Spinks asked if people with lived experience have been included in the development of an action plan. Randy replied that Joe Caldwell recently conducted a survey that gathered feedback about syringe services and disposal habits among people who inject drugs. The survey results helped to inform the action plan.

The regional Department of Health and Human Services (HHS) office in Kansas City has chosen Iowa to promote syringe services. The IDPH will share information as it is available regarding HHS's focus in Iowa.

Sam Smith stated that patients at the clinic she works in are reporting disposal of syringes at local parks and asked if this is the type of material to be added to the position paper. Randy replied that those types of stories are ideal to support syringe service programs.

Douglas LaBrecque asked if there was support from the governor's office pertaining to syringe services programs. Randy answered that the representative from the governor's office approved the action plan which includes legislation to implement syringe services programs.

### *Office of Medical Cannabidiol Update*

Presented by Randy Mayer

Randy announced that he has requested to step away from his role as the Director of Medical Cannabidiol after the new Behavioral Health division director is in place. Randy shared that there is now a second manufacturer, Iowa Relief, that will be producing products with both CBD and THC. Their first product has only CBD.

Med Pharm Iowa has released a vaporizable product with a high CBD to THC ratio (20:1).

Randy spoke about the current vaping dangers that have been in national media, and that unregulated THC and cannabis products were identified as the cause of recent illness and deaths. It is thought that vitamin E acetate, used as a carrier oil, is one potential toxin, although there may be others.

There have been several patient petitions submitted to the Medical Cannabidiol Program for consideration. The addition of PTSD to the list of approved conditions is currently under review. Opioid tolerance was denied. "Chronic pain" was approved and will be considered by the Board of Medicine now. Corticobasal degeneration has been approved by the Board of Medicine with

an October 16, 2019, release date. "Severe Intractable Autism with Self-Injurious or Aggressive Behaviors" (non-pediatric) was approved and is under consideration by the Board of Medicine.

The bill to remove the 3% THC cap and replace it with a 25-gram limit over 90 days was vetoed by the Governor. The Governor supports the 4.5-gram limit proposed by the Medical Cannabidiol Board. The legislature will have to reconsider the bill next year. Other provisions in the bill were to require pharmacists or pharmacy techs at dispensaries, to allow practitioners to have access to the registry, and to have the Iowa Department of Public Health issue registration cards instead of the Iowa Department of Transportation.

Roger Lacey asked if there was IDPH representation at medical board meetings. Randy replied that the assistant director of the IDPH facilitates the meeting and there are opportunities for department staff members to present to the board. Roger also asked if any consumers were on the board. Randy answered no, but there is an open period during meetings where community members can speak to the board. The next meeting is November 1, 2019.

### *USCA Debrief*

Roma Taylor facilitated a debrief and sharing session from the United States Conference on AIDS (USCA). Roma shared about sessions that she attended, including multiple ending-the-epidemic workshops and commented that presenters emphasized the importance of planning and including the community, specifically priority populations, in the planning process. Other factors were highlighted, such as having a dedicated staff person to champion the plan, building a diverse workforce, developing timelines, being available to the community outside work hours, and integrating comprehensive plans with ending-the-epidemic plans. There was a town hall toolkit available from one of the sessions and Roma will share with the group.

Darla Peterson (guest) also attended the conference. Her take-aways were to promote having providers talk with patients about U=U. Darla added that a survey had been conducted for providers (primarily infectious disease practitioners) in multiple states and results showed that 69% of providers in Iowa did not talk about U=U. Additionally, the survey showed some Iowa providers did not agree with telling their patients that condomless sex is okay if a person is virally suppressed. Darla heard an important point for us to remember; that  $V \neq V$  (viral load does not = value). Darla also found a session on HIV outbreak detection and response quite interesting. Representatives from Massachusetts, Indiana, and Texas discussed the outbreaks in their respective areas. Darla stated it would be valuable to listen to their lessons learned, plan for a disease outbreak, and be prepared.

Mary Hightower (guest) attended and suggested that a presentation called "The Power of Storytelling" might be good to bring to Iowa.

Ashlee Folesom (guest) attended several different sessions related to hepatitis, harm reduction, ending the HIV epidemic, opioid epidemic, and PrEP. Ashlee provided her notes for reference.

Tami Haught commented that she would like to see more people living with HIV go to USCA. Tami also offered that there was a community call to action to educate Dr. Redfield of the CDC about the impact of cluster investigations and molecular surveillance on people living with HIV and to call for a moratorium on cluster investigation and molecular surveillance until criminalization laws have been addressed. Additionally, Tami mentioned that it is important that the community be engaged in negotiations with Gilead about Truvada pricing.

## New Business

*Membership, Orientation, Bylaws, and Engagement (MOBE) Committee Update*  
Presented by Colleen Bornmueller, Biz McChesney, and Roma Taylor

Biz provided an overview of recent MOBE meeting agenda items. In August, the group discussed national community engagement research collected by an IDPH intern, reviewed the CPG Application Online Member Application, and reviewed the membership survey and small group feedback from the June meeting.

Roger Lacey asked if there was a way to provide feedback to the MOBE committee. Biz answered that any feedback is welcome and to please email her with any thoughts or include them on the meeting checkout.

Roma provided an overview of findings from the small group feedback from the June meeting. Biz talked about the next steps.

Roger asked about providing stipends for consumers who serve as CPG members. Biz answered that the subcommittee will be looking into what other states are doing and will report back to MOBE on findings.

See presentation for additional information.

*Iowa Strategic Planning Update*  
Jordan Sehla and Holly Hanson

Jordan spoke about developing a process to start planning for Iowa's next statewide plan. Holly provided an overview of interim activities, to include reviewing other state plan examples and developing a steering committee. Jordan went over the agenda items of the first steering committee meeting. The steering committee is made up of the following members: Randy Mayer, Biz McChesney, Holly Hanson, Jordan Selha, George Walton, Colleen Bornmueller, Roma Taylor, and Roger Lacey. A discussion was held regarding language sensitivity,

community input, and plan structure. Holly then provided information about the next steps. The steering committee will be gathering input about language and looking at models of community engagement. The next steering committee will be September 19, 2019.

Kathryn Edel asked if there were other state plans that resemble Iowa's landscape. Holly answered that some state's ending the epidemic plans look like Iowa's current comprehensive plan. Illinois, Texas, and Washington's plans may be relevant to Iowa. Tami Haught added that the Texas plan involved the community and she felt that was very important. Roger Lacey commented that plans varied greatly on content and level of engagement, and agreed that community involvement is key. Holly added that breaking the plan out into domains and developing them separately is key. Roma commented that Texas had several different methods to engage communities (surveys, meetings, events, etc.).

See presentation for additional information.

### *Washington HIV Community Engagement*

Presented by Lydia Guy Ortiz and Vanessa Leja (Washington State Health Department Staff)

Lydia and Vanessa provided an overview of Washington's HIV community engagement structure, which included a history of their HIV Planning Steering Group (HPSG), guiding principles and systems; advisory groups; HIV Stakeholder Villages; and HIV Special Emphasis Workgroups.

Colleen Bornmueller asked how people are recruited to participate. Vanessa answered that partners across the state are heavily relied on to recruit. Area service/medical providers and HPSG members are also utilized to recruit. Jorden Sehla asked if the villages are population-based or subject-based. Vanessa answered that it depends on the type of information that is being gathered by the group. Donald Baxter added that there are similar population characteristics between Iowa and Washington and asked how all communities are being involved. Lydia and Vanessa both answered that they have to balance feedback and prioritize engagement across that state.

Vanessa ended the session by covering the strategy for how Washington State will update their End AIDS plan and include HSGP in the process. Angela Speers asked about the duties of the HIV Aging Coordinator that was mentioned who focuses on the aging population of PLWH. Vanessa stated the duties include facilitating community focus groups to gather information about disease management, financial concerns, etc. Duties also include developing a plan to support the aging population.

See Presentation for additional information.

## *Cluster and Outbreak Detection and Response*

Presented by Randy Mayer

Randy provided a presentation that covered the purpose of cluster and outbreak detection and response, which included surveillance mechanisms, data reporting, data security measures, as well as methods of investigation and intervention.

Douglas LaBrecque asked why Iowa has a criminal transmission law. Randy answered that the legislature put this in place in 1998, but that it was updated with community support in 2014. The law is broader than HIV and includes other infectious diseases, including TB, hepatitis, and meningococcal meningitis. Additionally, data released by the IDPH varies. For example, TB results can be released with a subpoena, while HIV results are very difficult to obtain under the law and only HIV diagnostic test result information can be released with a court order. HIV viral load information cannot be released.

Conner Spinks asked if informed consent is facilitated at collection when patients have HIV labs done at their medical provider. Randy replied that nothing requires informed consent for the reporting of these data to the IDPH. He described a theoretical case of a newly diagnosed person who, if given the opportunity to provide consent, might make critical decisions at that time that could affect his/her overall care negatively.

Angela Speers asked who pays for genetic testing. Randy replied that genetic testing is paid for under many mechanisms, which includes Ryan White funding.

Doeglas LaBrecque asked about the HIV medication standard of care. Randy answered that the genetic testing is generally completed before a patient is started on treatment (except in the case of rapid START). All laboratory results automatically get reported to the IDPH, usually electronically.

See presentation for additional information.

### *Small Group Activity & Debrief*

Three small group activities were held including 1) CPG feedback with the community co-chairs, 2) cluster and outbreak detection and response activity, and 3) discussion and questions with Washington Health Department staff.

Roma Taylor, who facilitated the CPG feedback with community co-chair discussion, said that she will compile all of her group's information and share outcomes and/or next steps.

Vanessa Leja, who facilitated the discussion and questions with Washington HD staff, talked about integrating all planning groups and engaging people in priority populations. There were

discussions about community engagement and community planning and the importance of making the distinction. Washington's HPSG has a different makeup and structure, and medical providers make up a significant portion of HPSG, so the dynamics are quite different from Iowa's CPG.

## Related Work Group Reports

### *Quality Management*

Presented by Katie Herting, IDPH staff member

Annie Rodruck (IDPH staff member) talked about the consumer needs assessment that goes out every 3 years. The assessment is completely confidential and conducted online. It will be open for 8 weeks and people will get a gift card for completing the assessment. Katie added that for the first time, there are 2 tracks, one for people living with HIV and the other is for people who are not living with HIV or do not know their HIV statuses. People can receive their gift cards from their case managers or have them mailed to an address of their choice. Annie is asking for assistance in testing the survey next week and will send the test survey to the CPG members. The survey takes 30-40 minutes to complete.

Holly Hanson asked if CPG members had a chance to review the questions. Biz answered, yes, the questions were sent out in a Friday Facts email for CPG to review. The testing is focused on system functionality, not content. Holly added that the stigma and Adverse Childhood Experiences (ACE) questions remain on the survey. Resilience and HIV injectable medication questions have been added. The prevention questions include PrEP access, awareness of services, testing history/needs, etc.

### *Disrupting Racism*

LeeVon Harris

LeeVon said that Roma Taylor has been added to the Distributing Racism group. There will be a workshop at the IDPH's Technical Assistance meeting on October 16, 2019, for all contractors. Attendees will watch a video series followed by participation in an activity. The health equity spotlight will resume and content will be created by the group. Jenna Sheldon provided an overview of the agenda for the TA meeting.

### *Public Relations*

Tami Haught

Tami announced that a webinar hosted by The Foundation for AIDS Research (amFAR), will be held September 24, 2019, at 11 AM PT titled *Ending the Epidemic*. Also, Positive Iowans Taking

Charge (PITCH) and the University of Iowa are hosting a World AIDS Day event asking presidential candidates to provide a 3-minute video, speaking to their personal experience with the HIV epidemic. Johnson County Public Health will also be conducting HIV testing at this event. A link will be included in the October University of Iowa newsletter for people to support the event.

### *Queer Health Committee*

Carter Smith

Carter reported that the first meeting of this group was held last night. The goal of the first meeting was for members to brainstorm what they want to get out of the group. The group will focus on queer health with the goal to be an agent of change. Contact Carter via email ([csmith@slandchc.com](mailto:csmith@slandchc.com)) to join the group.

### Other Business

Carter Smith emphasized meaningful engagement and thought CPG should explore ways to engage broader community members.

Roger Lacey would like to see more consumer involvement and more movement on providing CPG members with stipends.

Roma added that the IDPH intern looked at different planning groups and will be providing a report of findings. The report should start discussion about next steps.

Roger Lacey had some PITCH flyers available for CPG members.

### Checkout Completion

Roma Taylor asked members to complete and turn in their check-outs that will be sent via a Google Form . Roma asked members to provide feedback on the new online check-out form.

### Call to the Public

Roma Taylor asked for the call to the public. No public comment.

### Announcements

None

### Adjourn

Carter Smith motioned to adjourn the meeting. The motion was seconded by Roger Lacey. The motion was approved. The meeting was adjourned at 3:48pm.

Respectfully submitted,  
Cristie Duric